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Title: Current Treatment Approaches for Paediatric CFS/ME

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Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is characterised by persistent fatigue, which has a significant impact on functioning and is associated with other symptoms. Table one shows the characteristic features of the fatigue and the commonly associated symptoms. Post exertional malaise is a particularly useful symptom. Children will describe this as an increase in fatigue and symptoms after doing more than usual. For example, feeling too unwell to go to school on Thursday and Friday having been to school at the beginning of the week.

[insert table 1 here]

Diagnosis

If you think that a child has CFS/ME, you need to exclude other possible causes for their fatigue. A number of disorders can be excluded using screening blood tests (table 2). A diagnosis should be made if the child continues to experience unexplained and debilitating fatigue, for at least 3 months, that has significantly impacted on their social, occupational or educational functioning.

[insert table 2 here]

Why make a diagnosis?

Between 0.4 and 2.4% of children meet the diagnostic criteria for CFS/ME, so it is relatively common. This is consistent with a systematic review of prevalence of CFS/ME in adults of 0.76 (95% CI: 0.23–1.29) with clinical assessment. CFS/ME has a significant impact children, their families and the NHS. On average, children miss a year of school as a result of the illness, and some become bedbound. The illness has a negative impact on parents and siblings. Most mothers reduce or stop work with financial consequences. Children with CFS/ME use significant health care resources but few get a diagnosis. Making a diagnosis in a child gives them the opportunity to access specialist treatment.

The recovery rate without treatment is very low. About two thirds of children can be expected to recover with specialist treatment.

Treatment

Specialist treatment for paediatric CFS/ME aims for recovery so that children can do everything that they want to do, including full time education. NICE recommends three treatment approaches for paediatric CFS/ME: Cognitive Behaviour Therapy (CBT), Graded Exercise Therapy (GET) and activity management where CBT or GET are not available. Of these, the best evidence is for CBT. All of these approaches should all also include advice on sleep management, and may also be complemented with pain and mood management when needed.

Sleep Management

Most children with CFS/ME vary their wake up time depending on how they feel. This may explain the dysregulated hypothalamic pituitary seen in teenagers with CFS/ME. Explaining why their sleep pattern is unhelpful and supporting them to establish a regular wake up time throughout weekdays and weekends helps stabilise and regularise the circadian rhythm. Children should go to bed between 8 and 10 hours prior to their wake up time (depending on their age), and develop an appropriate bedtime routine prior to trying to sleep, including avoiding the use of bright screens including mobile devices, computers and televisions for up to 1 hour before bed. Children with CFS/ME may intuitively have begun to sleep for longer, resulting in a decrease in sleep quality. Optimising the amount of sleep, with an anchored bedtime and wake-up time will restore sleep quality. Day-night reversal should be corrected by gradually waking earlier each day. This should be done no faster than 1 hour every three days and some children will opt for a slower change.

Children should be encouraged not to nap in the daytime because this will reduce night-time sleep quality. If a child has to nap, allow a short nap (20-30 minutes duration), with the curtains open and the lights on, prior to 3:00pm.

Amitriptyline and melatonin are both used to help improve sleep quality. Most parents and children will want to try behavioural methods to improve sleep before medication. Very low dose amitriptyline can be helpful if children have significant pain and sleep disturbance. Melatonin can be used if children still have difficulty getting off to sleep having done all the suggestions above.

Graded Exercise Therapy (GET)

GET specifically targets physical activity, stabilising this and then gradually increasing it in a systematic way. GET is moderately effective in adults with CFS/ME, but as yet, there have been no trials in children.

The first stage in GET is a physical assessment (sit to stand, step test, and 1 minute balance test), and an assessment of the range and type of exercise undertaken during the week. Exercise targets are then negotiated with the child. Initial exercise targets (the baseline) should be the median amount of daily exercise done during the week, and may include, for example, slow paced walking. Once this is achieved every day for 1-2 weeks, children are advised to increase exercise slowly by 10-20% a week. They are asked to time their exercise to make sure they are completing the same number of minutes of exercise every day and to keep a diary of this. Once children are doing 30 minutes of gentle exercise each day, the exercise will increase in intensity such that they start doing aerobic exercise. Children should be taught how to manually monitor their heart rate to prevent them doing too much exercise.

Activity Management

Activity management is a component of CBT, but does not, as a standalone approach, have an evidence base. Anecdotally, it appears to work well, particularly as an early intervention and in straightforward cases where a child is able to engage in making behavioural changes and does not have significant psychiatric comorbidity. It tackles the same patterns of activity as GET, but focusses on a broader range of activity (rather than only physical exercise). Activity management may well be working in the same way to GET.

Activity management is aimed at overcoming the unhelpful patterns of activity that arise as a response to being chronically fatigued; that is, a relatively active boom and bust pattern of doing lots of activity, followed by doing very little, or a low active pattern of a significant reduction in overall activity levels. After a period (typically 1 to 2 weeks) of recording activity levels, distinguishing high energy activities (those activities that are physically, cognitively or emotionally demanding for the individual) from low energy activities (those activities that are not demanding and do not exacerbate fatigue), a 'baseline' can be established. This is the median amount of high energy activity during the monitoring period. Once the child has sustained this level of activity for 1-2 weeks without significant payback, the activity level is increased by 10 to 20% every week. Recording activity levels can help children to notice whether they are doing the same each day or varying their activity.

Cognitive Behaviour Therapy (CBT)

There have been 5 randomised control trials of CBT for CFS/ME in children which have shown that this is an effective treatment approach, delivered face-to-face (10 sessions), via the telephone or as online therapy. CBT incorporates activity management and GET, with the cognitive components facilitating the behavioural change by addressing potential cognitive barriers such as fear avoidance beliefs.

CBT aims to tackle the behavioural and cognitive cycles that maintain fatigue. When an individual experiences chronic fatigue, on a good day, they may, for example, try to get everything done that they can, driven by thoughts such as 'I don't want to miss out'. On a bad day, they may do very little, driven by thoughts such as 'I am tired, I should rest'. Activity management and sleep management strategies are utilised to tackle the behavioural cycles. Cognitive strategies such as identifying unhelpful thoughts and challenging these, with the aim of developing more helpful thoughts proceeds alongside the behavioural programme. Attention is also shifted away from the symptom of fatigue using attentional retraining principles. Parental involvement in CBT is strongly recommended.

Returning to School

Returning to education is a crucial goal for the majority of children with CFS/ME. The challenges of the school environment for a child with CFS/ME include sitting in the classroom for long periods, managing noisy environments like school corridors between classes, and maintaining their attention and concentration. Using activity management (either as a standalone treatment or within CBT), a graded return is indicated. It is best to spread attendance evenly across the week, rather than to attend for several hours on one day and not attend the next day. Children should be encouraged to take regular rest breaks (5 to 10 minutes may be sufficient). They may need support with managing noisy environments, and, for example, being allowed to leave a class 5 minutes early to navigate the corridors may help in the early stages of the return to school. Special considerations for examinations such as taking the exam in a quiet room, and being given extra time, may be helpful in the short-term, but should not be needed in the long term once the child is recovered from CFS/ME.

Symptomatic Management of Pain

Children with CFS/ME can experience high levels of pain. If over the counter painkillers such as paracetamol and ibuprofen do not provide effective pain relief, a small dose of amitriptyline can be

prescribed. Opiates don't tend to help much and because of the increased risk of side effects, are best avoided. Psychosocial strategies may be useful, and referral to specialist pain services can be considered if necessary.

Managing Psychiatric Co-Morbidity

Around one in three children with CFS/ME have symptoms of depression and an even higher proportion have symptoms of anxiety, particularly social anxiety and separation anxiety. Using questionnaires such as the Revised Children's Anxiety and Depression Scale (RCADS) can help with identifying such co-morbidities, particularly if the cognitive and emotional symptoms (e.g. global negative thinking patterns and low mood and/or irritability in depression) rather than the somatic items (e.g. tiredness in depression) are considered.

There is little evidence on how to treat children with CFS/ME and comorbid mood problems. CBT is an evidence based treatment for both CFS/ME and depression/anxiety in children. Clinicians should develop an individualised formulation with the children and their family in order to determine maintenance cycles and therefore treatment targets and the sequence of the required interventions.

With children who are depressed, antidepressants (fluoxetine) may be helpful where the individual is severely depressed that their hopelessness and/or lack of motivation is impacting on their ability to engage in talking treatments, including in fatigue management. Regular risk monitoring and management is also indicated.

Conclusions

Making a diagnosis of CFS/ME in a timely manner, and ensuring that a children has access to the available treatments, and ideally, is able to choose the treatment approach which feels most helpful to them, with the support of the clinician, is most likely to lead to positive outcomes, including a

return to full time education and being able to engage fully in sports, hobbies, social and family life. Outcomes for CFS/ME in children are very encouraging, with most children making a full recovery.

Further Reading

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Conflict of interest

EC is an unpaid medical advisor to the Association for young people with ME and the Sussex & Kent ME/CFS Society. No other conflicts of interest.

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Table 1. Diagnostic checklist for CFS/ME in children based on NICE guidance (2007)

Fatigue:

- ☐ Debilitating persistent or relapsing fatigue for at least 3 months, but not life-long.
- ☐ Not the result of ongoing exertion and not substantially alleviated by rest.
- ☐ Post-exertional malaise and/or fatigue, typically delayed (e.g. by at least 24 hours) with slow recovery over several days.
- ☐ No clinical evidence of other causes of fatigue
- ☐ Severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities.

And at least ONE of the following symptoms persisted/recurred during 3 or more consecutive months and did not predate the fatigue:

- ☐ *Sleep disturbance including unrefreshing sleep*
- ☐ *Muscle pain*
- ☐ *Joint pain*
- ☐ *Headaches*
- ☐ *Painful lymph nodes without pathological enlargement*
- ☐ *Sore throat*
- ☐ *Cognitive dysfunction*
- ☐ *General malaise or 'flu-like' symptoms*
- ☐ *Dizziness*
- ☐ *Nausea*
- ☐ *Palpitations in the absence of identified cardiac pathology*
- ☐ *Hypersensitivity to touch/noise/light*

Table 2. Screening blood tests recommended by NICE

Full blood count	Screening blood tests for gluten sensitivity
Creatinine, Urea and electrolytes	Serum Calcium
Thyroid function	Creatine Kinase
Erythrocyte sedimentation rate/plasma viscosity	Ferritin levels
C-reactive protein	Urinalysis
Random blood glucose	